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ABSTRACT

Described is a home teaching program at the Boston Center for Blind Children which provides assistance to families of children (0- to 3-years-old) who have visual impairments, often accompanied by severe developmental disorders such as seizures and psychomotor ratardation. It is noted that during home sessions the teacher instruct the child, serves as a model for the family, and reinforces positive family efforts. The instructional program involves an individual prescriptive treatment plan which is based on results of The Developmental Checklist, a social maturity scale, and conferences of the psychologist, social worker, and teacher. The following stages of home visits are discussed: discussion of progress since that last teaching session, reinforcement by the teacher and provision of alternate suggestions on techniques that were unsuccessful, demonstration of new activities and observation of family interaction and infant responses, general discussion, and suggestions of followup activities. Each child is said to be evaluated on an individual basis through use of the Developmental Checklist. A case history is presented to illustrate home teaching dynamics. Appendixes include samples of the graphic record form, the home teaching record form, and goals of a treatment plan; a bibliography; and lists of materials and equipment. (GW)

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WHY SEVERELY IMPAIRED INFANTS AND THEIR FAMILIES NEED HELP

THE EARLIER - THE BETTER

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MAY 24, 1974

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Of course all babies are normal, healthy and thriving, becoming creeping, walking, and talking toddlers, becoming bicycle-riding, ball-playing children, until yours isn't. When an infant has a visual impairment and developmental retardation, it is not always apparent at birth. Often the joy of a new baby begins to diminish through the early months as parents notice their baby's eyes do not seem to focus on anything. Often parents' suspicions and fears increase if the natural developmental milestones do not occur. Parents may call their pediatrician, still wanting to believe that he will allay their fears. What may follow can seem like an interminable round of specialists, hospitals, tests, and evaluations that abruptly halt the routines of daily life, and lead parents to the still shattering shock that their child is blind and severely retarded. The facts are sometimes too overwhelming for parents to assimilate. There may be a confusing combination of feelings of anger at the doctor, at God, guilt, disbelief, or despair. The process of coming to terms with the knowledge of having a severely-impaired child is usually slow and painful. Families may feel isolated and helpless. The knowledge may put a strain on the marital relationship.

The normal gratification derived from parenthood or from siblings is often denied the family of a severely-impaired child. The infant may be unresponsive and passive, or fussy, hindering the development of a warm and positive relationship among family members. Parents watch the babies of friends and relatives thrive and grow, and watch their baby stay the same. They think there must be something else they can do for their child. There is!

II. HOW THE BOSTON CENTER FOR BLIND CHILDREN HELPS

The Boston Center for Blind Children is providing this help to families and children from birth to 3 years of age who have visual impairments, who often also have severe developmental disorders such as seizures and psycho-motor retardation. The major focus of the program, to enhance the developmental potential of each child, is achieved through a home-teaching program, based on the strategy of a family-teacher partnership. We have found this approach effective as it emphasizes the home, the best place for any infant, as an educational setting, and the family, the best teachers for their own child, as partners in the educational process.

The building and success of the family-teacher partnership depends largely on the teacher's ability to work with and through family members, to create an environment for effective interaction between them and their infant.

THE ROLE OF THE TEACHER IN FORMING A PARTNERSHIP WITH THE FAMILY

The effectiveness of a teacher in fulfilling the objectives of a home-teaching program is determined by the relationship he or she establishes with family members. The teacher will find it necessary to assume many roles in order to build this relationship.

Although the major focus of each session is to teach the child, the teacher is simultaneously serving as a model for the rest of the family. Rather than telling parents what to do to help their child, the teacher shows them what to do by demonstration and example. The teacher responds to the child in the way she hopes the family will react---by reinforcing positive behaviors of the child. Similarly, the teacher needs to support the positive efforts of the family as well. It is the responsibility of the teacher to fit herself into the existing structure of the home, in order to help families regain their unity, rather than to undermine their values and strengths. Therefore, the teacher plans activities for each session that will involve herself or himself, the infant, the mother, and any other family members who are there.

The teacher must also be able to determine the depth of understanding on the part of a family regarding the infant's abilities. She or he will gradually help them develop realistic expectations for their child by working together with them in determining goals for their child. In order to accomplish these goals, the teacher must be able to establish clear open lines of communication with a family to help them feel comfortable in talking about their child. Projecting an honest balance of concern and optimism, and being a non-judgmental listener are essential in developing a good relationship. As a guest in the home, the teacher must be restrained in dealing with misinformation, unrealistic statements, or family disagreements.

The teacher will also find herself in the role of confidante; she must be skilled in dealing with feelings that are often the most difficult for people to express. She must evaluate which feelings are best dealt with in the relationship between teacher and family, and which highly sensitive areas necessitate the help of another professional, such as the social worker. She must be accepting, understanding, tactful, and strictly confidential. In this way, she will usually gain the trust and respect of families, needed before she can help them.

III. THE HOME-TEACHING PROGRAM

Assessment and Planning

The home-teaching program is based on the development of an individual prescriptive treatment plan for each child dependent on his present skills. When a child has been accepted into the program, the teacher administers The Developmental Checklist* to determine what skills the child possesses in each of the seven developmental teaching areas: gross motor, fine motor, expressive language, receptive language, social skills, self-help, and orientation and mobility. The advantages of using this guide are that the measurement of skills is not dependent on visual responses, that skills are finely dissected so that even a severely-limited infant can be evaluated,

*See Appendix

and that a curriculum can be generated directly from the initial assessment. An interview takes place with the parents and psychologist at the Center at which time the Maxfield-Buchholz Adaptation of the Vineland Social Maturity Scale is administered, a scale based on parental reporting combined with clinical observation of behavior.

On the basis of this initial evaluation, an individual treatment plan or curriculum consisting of goals in each developmental area is established for each child. The teacher works with the parents in establishing these goals. Each goal is a step in the attainment of a skill, and corresponds to a set of activities that have been designed to help a child achieve that goal.

The psychologist, social worker, and teacher confer and assess objectives for parents, that are also individual based on what kinds of problems each family seems to be having in making adjustments to the presence of an impaired child. These objectives give direction and insight for the teacher in her relationship with the family, and serve as a basis for the social worker in her contact with them.

Although the BCBC maintains a consultative staff of a psychologist, psychiatrist, pediatrician, and social worker for assessment and planning for day and residential children, it was decided to utilize the community medical facilities and a more limited Center staff for the home-teaching program, for several reasons. First, each child had undergone extensive medical evaluations either at Children's Hospital or New England Medical Center, and continued to be followed by specialists in neurology, ophthalmology, pediatrics, and physical therapy. It was felt in the best interest of the child and in the development of communication between the local medical community and the educational field to coordinate our efforts on an ongoing basis.

Quite secondarily, it was impossible to obtain more consulting time from the staff, and costly. Since it was also impractical to expect families to travel to the Center on a regular basis, especially where other children were in the home, utilizing specialists in the community circumvented these problems.

Implementation

The goals for children and their families are implemented at each home visit through activities planned to involve infant, teacher, and family. The activity cards, part of the Developmental Teaching Guide, provide the curriculum. The teacher maintains a broad structure and organization for home visits, and allows flexibility so that each visit is handled differently to meet the needs of the individual family. However, the following five components are almost invariably present in the structure of any home visit:

1. Brief discussion of the period since the last session. How has progress been on the activity(ies) with which the family has been asked to follow through?

2. Interpretation - reinforcement by the teacher - alternate suggestions for unsuccessful techniques.

3. Activity(ies) - Demonstration by the teacher of appropriate verbal and physical interaction during the activity. Observation by the teacher of how the family interacts with the infant during the activity. Observation of the infant's responses.

4. Discussion with the family about the activity and opportunity to provide general information, answer questions regarding the handicapping condition and help with problems raised; opportunity for teacher and family to chat.

5. Suggestions for activities to follow through on until next visit.

Each home teaching session is documented by the teacher as an aid for curriculum planning and evaluation*.

* See Appendix for forms.

Evaluation

The goals established for each child and family are ongoing rather than being set for a specified period of time. The rate of progress in such severely-imapired children is quite variable and usually extremely slow. At the end of each academic year, the Developmental Checklist is re-administered and goals revaluated for the forthcoming year. From the beginning of the project, progress was measured in two ways: during the initial year of the program (while the Developmental Teaching Guide was being developed) the Denver Developmental Screening Test was used. The Denver scale provided a measure of the number of developmental months attained. The scale proved to be relatively inappropriate for this population as a great number of skills depended on a visual response, and therefore had to be eliminated. Furthermore, steps between skills were too great to demonstrate the small gains which could be expected in this particular population. Utilizing the Developmental Checklist provided a measure of the percent of goals attained in comparison to the number of goals established for each child. Therefore, each child was truly evaluated on an individual basis irrespective of the achievements of a normal population. This was felt a more valid method of dealing with the evaluation of severely-impaired infants where a comparison to a normal population would serve no useful purpose.

The teacher also maintained a graphic evaluation of characteristics observed in all the families. This graph provided a visual summary of the progress of the family in categories applicable to all*.

*See Appendix

IV. THE HOME-TEACHING PROCESS: A CASE HISTORY

The specifics of the home-teaching process are less easily described than the philosophy and nature of the program. As these specifics vary from family to family, the process can best be illustrated by following the course of one child and his family.

Referral

B. was referred to the BCBC preschool community program by his physical therapist. She was seeing B. for physical therapy for one hour monthly at a school for Cerebral Palsied children. She felt that B. needed both a more intensive and a more extensive program that would deal with his visual impairment as well, and involve his family. The teacher called B's. mother, introducing herself and the program and arranged an initial visit to the home.

Initial Visit

B. and his mother, who was expecting a second child in 5 months, greeted the teacher. B. was an attractive and lively 2 year old boy rolling on the carpet of a nicely furnished, but cluttered, apartment. While the teacher and B's. mother became acquainted, B. was observed to use his residual vision to reach for a stacking toy the teacher brought with her. B's. mother filled out the application and signed waivers to release medical records. The teacher explained the program more fully and B's. mother expressed her desire to participate. Arrangements were made for a visit the following week.

Coordination

The teacher called B's. physical therapist to inform her of his acceptance into the program. Arrangements were made for the physical therapist to visit the home every month to explain appropriate exercises (in terms of the cerebral palsy) on which the teacher would help B's. mother follow through.

Medical Records

Records were sent for and received. The following information was then available for the teacher to interpret educationally.

The records indicated that B. was the product of a full-term pregnancy, and considered normal at birth. When he was 3 months old his parents noticed wandering eye movements and a lack of visual responses. He was seen by an ophthalmologist shortly thereafter and was diagnosed as having Optic Nerve Hypoplasia. B's. mother mentioned he still did not roll over, and further evaluations were arranged. The neurologist diagnosed spastic cerebral palsy with a question of a psycho-motor delay.

SESSION II

The focus of the second home visit was on administering the Developmental Checklist. While measuring B's. skills, the teacher used the opportunity to help his mother talk about him. The teacher interpreted that B's. mother found learning of his physical disability easier to accept than his blindness which she felt devastating news. The teacher helped explain the meaning of the ophthalmologist's diagnosis, and both observed that B. did use whatever sight he has.

The Developmental Checklist was administered through direct observation and questioning of B's. mother.

Summary of Developmental Checklist Data:

Self-Help: B. was able to feed himself finger foods and hold his own bottle. He had no dressing or toileting skills.

Gross Motor: He could sit independently and traveled by rolling. He could bring himself to his hands and knees into the crawling position.

Fine Motor: B. grasped small toys with his thumb and forefinger, and used two hands at midline. He showed preference for his left hand.

Expressive Language: B. babbled and vocalized to his toys. He imitated speech sounds.

Receptive Language: B. responded to his name and "No-No", and to simple verbal requests such as "Give it to me."

Orientation and Mobility: B. could point to a few gross body parts and could localize sounds in the room by rolling toward them.

Social Skills: B. responded to physical and verbal play by laughing. He would vary his behavior according to the reaction of others. His play was solitary.

SESSION III

On the third visit the teacher brought a copy of the goals generated from the results of the Developmental Checklist and discussed them with B's. mother. She commented that it seemed like an "awful lot of things to do." The teacher decided then to take one area at a time, and initially suggesting only one activity for the mother to work on between visits. A fine motor goal was chosen. To use two hands, one holding, the other manipulating. Since B. showed interest in the stacking toy the teacher had left on the first visit, she decided this toy might be a good starting point. Sitting behind B. on the rug, she guided his hands to hold the toy with one hand, and stack with the other. She engaged in a great deal of verbal play while doing it, saying the colors and verbally reporting what they were doing during this activity. It became a game to B. and he enjoyed being successful at it. B's. mother, who observed this session from her seat on the couch, said her husband would probably try the activity in the evening with B.

SESSION IV

When the teacher arrived for her fourth visit, Mrs. B. offered coffee and seemed anxious to talk. She said her husband had been successful in working with B. on the stacking toy, but B. didn't seem to respond to her efforts. Shifting the focus of the visit, she said she wasn't receiving the attention of her family as she had with her first pregnancy. She said she was worried about the new baby being normal. The teacher suggested that perhaps her family might feel uncomfortable or even anxious about discussing her pregnancy.

She agreed and said she felt better talking it over with someone. After talking with the mother, the teacher brought B. to her lap and began playing a game of naming body parts, and singing a rhyme about them. Mrs. B. seemed less tense, began to join in, and seemed proud to show off B's. skills in this area.

The following week Mr. B. called the teacher to tell her his wife had delivered a few weeks early, but mother and child were doing fine. The teach called Mrs. B. at the hospital and asked to visit her. At the hospital, Mrs. seemed relieved that the waiting was over, and the doctors said the boy was fine. She stated, however, that she really wouldn't believe it until the baby rolled over. Mrs. B. said she would call the teacher to arrange the next session when everyone was settled at home.

Mrs. B. did not call. Two and a half weeks later the teacher called her. Mrs. B. was extremely upset because the baby had been hospitalized with pneumonia. Mrs. B. called the following week, saying that the crisis had passed but B's. behavior had become increasingly negative since the baby's arrival home.

At this writing, the teacher had arranged for the next visit and planned to work with Mrs. B. around her feelings about B. and his response to the new baby. This visit will be in conjunction with the social worker. B's. behavior was hindering the achievement of skills, and thus would have to be dealt with before any more progress could be made.

CONCLUSION

This case history was selected since it demonstrates the mutli-faceted aspects of a home-teaching program. In this case, the teacher was required to serve in several capacities besides teacher for B., also dealing with several people in varying situations. She had to coordinate her program with the physical therapist; she had to deal with the anxieties of the mother during her pregnancy; she served as a model for Mrs. B., to interact with

her son in a more positive manner; she needed to deal with Mrs. B's. negative image of herself as a mother; she had to be supportive during a crisis. Finally, she had to begin to deal with B's. emotional problem before she could effectively resume teaching of skills.

A comment of Mrs. B. seems to express the raison-d'etre of this program. "I'm not sure I could have continued to face this alone any longer. I used to tell people that B. had been sick and that was why he is slow. I feel so much better being able to tell them the truth." This is how we measure the success of our program. The process of adjusting to the birth of an impaired child is a uniquely personal thing. Some families never adapt to it---others do so remarkably. We try to help each family find its own solution through discovering joy in the accomplishments of their child, accomplishments that they themselves made happen.

APPENDIX

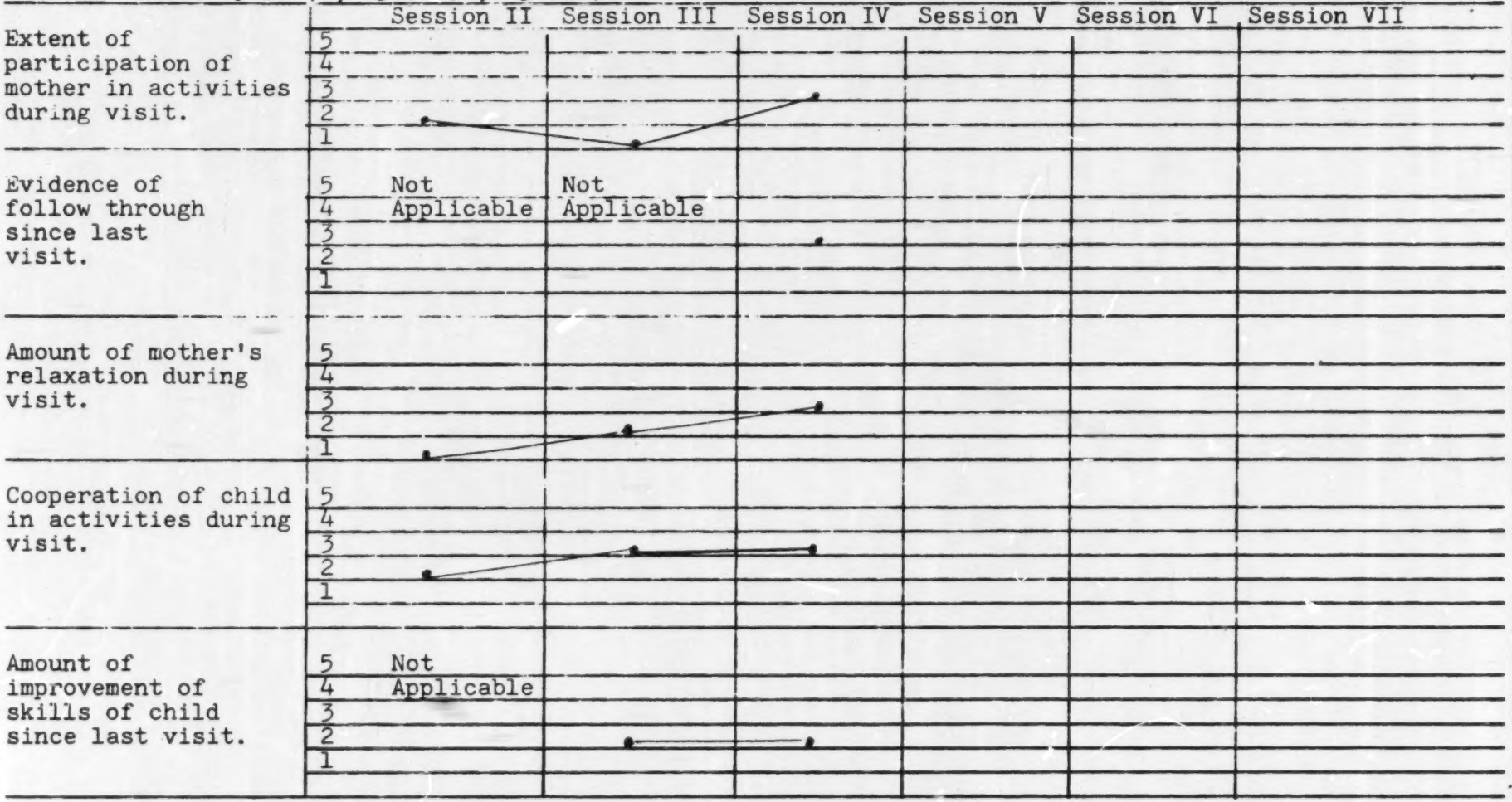
1. GRAPHIC RECORD FORM
2. HOME-TEACHING RECORD FORM
3. TREATMENT PLAN: GOALS
4. BIBLIOGRAPHY
5. MATERIALS AND EQUIPMENT

(1)

SAMPLE GRAPHIC RECORD FORM

NAME: B.

DATE OF VISIT: 3-11-74, 3-18-74, 3-26-74



(2)

SAMPLE HOME-TEACHING RECORD FORM

NAME: B. DATE OF VISIT: Session III

	OBSERVATIONS	SUGGESTIONS	COMMENTS
MOTOR SKILLS (gross and fine)	Stacking toy: sitting behind B., held toy with right hand with assistance. After assistance with one disc, removed others independently with left hand. Allowed hand to be guided to stack toy but could not find hole independently.	Suggestion made that since B. seemed to enjoy this toy, to play with it with him this week.	Mrs. B. said her husband would probably try it this evening. She seemed surprised that B. could manipulate it.
SELF-HELP	No work done in this area this visit.		
LANGUAGE (receptive and expressive)	B. understood the direction, "take it off", using the stack toy and seemed to understand "put it on" when paired with the action. He imitated the teacher when she said "take the blue one, he said "b-b"; he babbled in response to the teacher.	It was suggested to continue to encourage his attempts at repeating sounds and praise him. Generally verbalize what you are doing whenever you do it; e.g. "Let's sit on the rug and look at this toy."	Mrs. B. directed her comments to the teacher primarily during the session without talking to B. She said "Good" to him once.
SOCIALIZATION	B. ignored his mother during the session and only turned around to the teacher twice when praised. He was engrossed in the toy. However, he laughed each time the teacher said "thank you" when he gave her a stacking disc.	No suggestions were made by the teacher.	

(2) Continued

SAMPLE HOME-TEACHING RECORD FORM

NAME: B.

DATE OF VISIT: Session III

	OBSERVATIONS	SUGGESTIONS	COMMENTS
ORIENTATION AND MOBILITY	B. was rolling around the rug upon the teacher's arrival. He avoided the furniture and large objects in his way. He rolled toward the television when loud clapping came on.		Mrs. B. commented that she had a lot of furniture in a small apartment and hoped to move to a bigger apartment after.

NAME: B.

TREATMENT PLAN

GOALS:

Gross Motor Skills

1. To rise from lying to sitting position.
2. To begin to crawl.

Fine Motor Skills

1. To put small objects in and out of a container.
2. To use wrist action in grasping objects.

Expressive Language

1. To repeat sounds and words on request.

Receptive Language

1. To comprehend simple verbal directions.

Self-Help

1. To take the spoon to his mouth, closing his lips over it.
2. To drink from cup when held.

Social Skills

1. To imitate actions of others when demonstrated.

Orientation and Mobility

1. To point to several body parts when requested.

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(5)

MATERIALS AND EQUIPMENT

Skill	Recommended	Company	Price
1) Motor Development	Dolphin Crawler	Childcraft Company 150 E. 58th Street New York, New York	$10.95
	Economy Mats	Skill Development Equipment Company 1340 N. Jefferson Anaheim, California	From $7.95 to $45.00 dependent on size
	Bolster	Sears Roebuck Company	
2) Auditory	Baby Shapes Set	Childcraft Company 150 E. 58th Street New York, New York	$3.95
	Rhythm Band Set	Developmental Learning Materials 7440 Natchez Avenue Niles, Illinois	
	Wristbells		$ .65
	Xylophone		$2.85
	Tambourine		$4.25
	Maracas		$1.60
	Ring-a-lings	J. L. Hammett Company Braintree, Mass. 02184	$5.50
	Bell Mobile	Creative Playthings	$7.95
	Wind-Up Radio	Fisher Price	
	Hohner Ankle Bells	Childcraft Company 150 E. 58th St. New York, New York	$2.40

(5)
Materials and Equipment (Cont'd)

Skill	Recommended	Company	Price
3) Tactual	Beanbags	Developmental Learning Materials 7440 Natchez Avenue Niles, Illinois	$3.00
	Spongeballs	Same as above	.80
	Feeling Ball	Creative Playthings	$4.95
	Clutch Ball	Childcraft Company 150 E. 58th Street New York, New York	$3.95
4) Self-Help	Desk 'n Things Set	J. L. Hammett Company Braintree, Mass. 02184	$32.50
	Baby Swivel Spoon	J. A. Preston Company 71 Fifth Avenue New York, New York 10003	$2.65
	Plastic 6 ounce bottles	(Local store)	
5) Manipulative	Colored Stacking Discs	J. L. Hammett Company Braintree, Mass. 02184	$3.50
	Kittle in the Kegs	Same as above	$1.20
	Chunky Nuts	Childcraft Company 150 East 58th St. New York, New York	$3.95